

September 20, 2012

Dear DD Task Force,

I hope that you were able to review the letter I sent regarding Respite Revamp. Given the huge need in the community and particularly the self-identified need of respite among the no-paid caseload, I believe that group respite is the most cost effective, stable, sustainable and reliable service that we could provide to aid these families. Regular, reliable respite is critical in avoiding crisis.

From not only the experiences we had but listening to the many people I communicate with who need or utilize respite care, reliability and staff turnover are the major concerns. Too many times the care-giver does not show up or is not available when needed. When this occurs, rather than being respite, the “respite” leads to crisis. Crisis is what we want to avoid.

I want to share to experiences that I have had this week.

1. This is a message that I received from a teacher I know who has a child with developmental disabilities, had been on the medically fragile caseload when during birth-3 (and was very happy with the care and services they received) but now that Sophia is almost 4, the mom had different experiences when dealing with DDD. The quote below is verbatim from her question to me.
 - a. “hi cheryl,
I called the DDD office, to see about re=applying for Soph's stuff since she will be four, and in doing so, I asked about any other services we might be eligible for the lady said, basically, that we needed to contact other families who had gone through the system and ask questions of them...to try and figure out the system...
do you have any thoughts on where we might head to see if I am plugged into the system properly”

Is this the type of caseworker that clients have now?

I will be meeting with this mom and reviewing her paperwork with her, offering suggestions for help. She is a single mom, Sophia has

survived Wilm's Tumor (Kidney Cancer) in addition to living with a trach and other developmental/medical disabilities.

2. This week, Melvin, an 18 year old, who has stabilized at Fircrest was denied long term placement. There are no safe alternatives in the community for him and the family has looked at a minimum of 9 placements. No one will take Melvin.
 - a. Melvin attends Roosevelt High School in Seattle. The family is very pleased with the education. They just had his IEP and it is clearly stated that Melvin needs 1:1 at all times.
 - b. The teacher told Melvin's mom that they have 4 Instructional Assistants that she rotates through on a 1-2 hour rotation to be Melvin's 1:1 because Melvin is so intense and exhausting. This was not news to his mom but clearly identifies that Melvin is extremely intense and it is not safe for him or the caregiver to not have backup or relief.
 - c. Melvin enjoys being around people and has adapted well to the environment at Fircrest and is safe and stable. Moving him would send him into crisis again.
 - d. **DDD has informed the mom that since there are no homes that would work for Melvin in existence, they have approved for Melvin to have his own home with 1:1 caregiving.**

3. **As a parent and advocate I have to think that the decision of DDD in the case of Melvin is not only irresponsible and dangerous but indicates how the system is set up to produce crisis. Why doesn't anyone see that the reason Melvin is stable is because he is now in an environment which has adequate, appropriate, stable supports which allow him to function at his optimal level? Isn't this the purpose of DDD? Why then, is DDD doing all it can to deny him these supports and push him into crisis?**

I hear over and over again that “people should not be in institutions” or “children should not be in institutions.” Those statements mean nothing and do not look at the individual’s needs. There are many things that I do not think should be – “people should not have disabilities,” “people should not be poor”, “People should all have meaningful jobs” or “people should not die.” The list is endless and irrelevant. We need to look at what is and work with what we have. Wishful thinking of the impossible is not a realistic vision to look at in attempting to manage these issues. This type of thinking only denies that these needs exist and gives these people a way to not think about the people who may need these services for survival.

I have stated previously that moving my son to a community home would be like putting him in a prison cell. It’s interesting that Melvin’s mom told me the same thing about Melvin. She is so fearful of what could happen if Melvin was in his own home with only one caregiver. She knows that Melvin would be locked in a room by himself because the caregiver would not be able to safely care for him. She is afraid of abuse given the fact that Melvin is non-verbal and there would be no others to oversee what was going on. There would be no backup. This is not a type of “community” existence. Just because someone lives in a “community” residence does not mean that they are in the “community.” This is a critical issue that the DD Task Force needs to look at.

The environment that is the Least Restrictive for that Person is the environment which allows that person to interact with and be part of the community to their fullest potential. As stated in the 1999 US Supreme Court Decision of *Olmstead*, for some that may be the institution.

One other point that I would like to make in regards to the case of Melvin. It is my understanding that the Home and Community Based Service Waivers should not cost more than what it would cost to have the person in the ICF/ID. Certainly supplying a house for himself with 1:1 caregiving would be much more expensive

for the state than allowing Melvin to stay at Fircrest. **The fact that the state is pushing for this much more expensive alternative for Melvin's care indicates to me that this philosophical issue about deinstitutionalization without regards to the needs of the person is the driving force behind decisions. It's not really the cost or the individual's needs which are the facts taken into consideration but how can we deinstitutionalize people – even if it is not in their best interest or less expensive.**

I have attached a copy of correspondence that I had with Don Clintsman and Mark Eliason in 2011 regarding the cost of care for the 30 highest costing DD community residents. The costs they have given me are for the direct care costs only, I believe. Either one of these men can correct me if I am incorrect or clarify what these costs do include. When looking at the annual average cost of care (Direct Care only) for these clients, the cost is a daily average of \$598.29 and an annual cost of \$218,375. Again, this is direct care only – the comprehensive cost of the RHC is less than this.

I am not telling you this so that people are made to go into the institution because I do believe that people need to be allowed the choice, as written in both the US DD Act and *Olmstead* but it also needs to be noted that DDD is not following the cost of care rules and is using the argument of cost inaccurately for those residents with the highest support needs. It IS NOT less expensive in the community and if these residents choose to live in the RHC (which would also be less expensive for their care) they should be allowed that choice.

Thank you,

Cheryl Felak